

DOE ELSI Program Emphasizes Education, Privacy

A Retrospective (1990-2000)

Aug. 2001. The following retrospective of the DOE ELSI program, including a listing of its products, was prepared by Daniel Drell, manager of the ELSI component of the DOE Human Genome Program, and Anne Adamson, Human Genome Management Information System (HGMIS).

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At a White House ceremony on June 26, 2000, President Bill Clinton announced that the Human Genome Project (HGP) had reached an astonishing milestone. HGP scientists had assembled a "draft" version of the human genome's entire sequence of 3.2 billion base pairs—the set of genetic instructions present in the nucleus of virtually every human cell. Flanked by Francis Collins of the National Human Genome Research Institute of the National Institutes of Health (NIH) and J. Craig Venter of Celera Genomics, the president reminded his audience that 99.9% of the genome sequence of any two humans is the same and that what unites us vastly exceeds what makes each of us unique.

Mr. Clinton noted that, from the perspective of DNA sequence, we are essentially the same, all members of one human race. Nonetheless, many of our individual features are attributed to the 0.1% (about 3.2 million of the total 3.2 billion) of unshared DNA bases scattered throughout the genome in a location pattern particular to each person. This diversity has been the focus of much research, genetic testing, attempts at commercial exploitation, and concern bordering on fear.

Even as the U.S. Department of Energy (DOE) began the HGP in 1986, project managers, researchers, and lawmakers recognized that the increasing knowledge about human biology and personal genetic information would raise a number of complex issues for individuals and society. In response to congressional mandates to identify and define such issues and develop effective policies for addressing them, DOE and NIH have devoted 3% to 5% of their annual HGP budgets to studies of the project's ethical, legal, and social implications (ELSI).

Among these implications and issues are the ability to predict future illnesses well before any symptoms or medical therapies exist; the privacy and fair use of genetic information with respect to employers, insurers, direct marketers, banks, credit raters, law enforcement agencies, and many others; the availability of large amounts of genetic information in largely unprotected data banks; and the possible discriminatory misuse of genetic information. One potential (though admittedly extreme) outcome of the HGP is that genome research and the wide use of genetic screening could foster a genetic underclass, leading to a host of new societal conflicts and exacerbating others of long standing.

In what has become the world's largest bioethics undertaking, the U.S. genome project's ELSI component is a model for others around the world and, nationally, has led to similar endeavors in related research areas. The DOE and NIH ELSI programs emphasize the privacy of genetic information, its safe and effective introduction into the clinical setting, fairness in its use, and professional and public education. The programs focus on ethical, legal, cultural, social, and psychological consequences that could affect policy development and service delivery.

In 1991 DOE narrowed its ELSI scope to concentrate on genetic education, the privacy and fair use of personal genetic information, and genetics and the workplace. As its portion of the total ELSI component, DOE supports peer-reviewed studies on the uses, effects, and implications of personal genetic information in various settings; its

ownership, access, and protection in computerized databases and tissue and sample archives; and commercialized products of genome research.

DOE also supports studies of ways in which society and its institutions deal with ELSI considerations surrounding the complex multigenic conditions and disease susceptibilities that, because they are common, are most often cited as concerns. DOE's goal is to democratize Human Genome Project information and make sure it is distributed widely.

Collaborations

To avoid unnecessary duplication of effort by their two independent ELSI programs, DOE and NIH have collaborated in a number of activities and maintained close communications over the years. The NIH-DOE Joint ELSI Working Group periodically consulted with program staff and assisted in coordination. Other collaborations involved several research projects; joint conferences and workshops; and programs supported with other agencies, organizations, and commercial companies. In January 2001, the DOE and NIH ELSI programs jointly convened a symposium, "A Decade of ELSI Research." It brought together many investigators supported by the two programs during the past 10 years to review ELSI accomplishments and foster additional research and collaborations.

Promoting Public Understanding

In keeping with its long-standing commitment to education, the DOE ELSI program promotes knowledge about the HGP and its ELSI implications to such groups as institutional review boards, medical professionals, genetic researchers, judges, policymakers, and the public. These efforts have included conferences, seminars, publications, videos, Web sites, and radio and television programs. A few examples are given below.

- One of DOE's major commitments to promoting public discourse and project accountability is its support of the Human Genome Management Information System (HGMIS), which disseminates information on all aspects of genome research to interested individuals and groups. Although not strictly an ELSI entity, HGMIS helps the DOE Human Genome Program fulfill its educational commitment by publishing and distributing HGP documents and knowledge both in print and via its extensive [Web site](#). HGMIS staff members also represent the project at symposia and other meetings and answer numerous questions and requests directly and through the Web. [HGMIS address: Human Genome Management Information System; Oak Ridge National Laboratory; 1060 Commerce Park; Oak Ridge, TN 37830 (865/576-6669, Fax: /574-9888, mansfieldbk@ornl.gov)]
- *Human Genome News*, the newsletter of the U.S. Human Genome Project, is published by HGMIS. *HGN* facilitates communication among genome researchers and seeks to inform the broader public about the project. [Free print subscriptions from HGMIS, copies downloadable from the [Web](#)]
- The 1996 color booklet *To Know Ourselves*, by Douglas Vaughan, is an overview of the underlying science of the Human Genome Project. [Downloadable from the [Web](#)]
- The DOE *Primer on Molecular Genetics*, written by Denise Casey of Oak Ridge National Laboratory in 1992, introduces the basic science of genetics. [Downloadable from the [Web](#)]
- Originally supported by DOE, [The Gene Letter](#) was first published in 1996 by Dorothy Wertz and Philip Reilly of the Shriver Center as a way to use the Internet for genetics education. Now monthly, the online newsletter is freely available to interested professionals and consumers.
- *Seeking Truth, Finding Justice*, a 3-hour television documentary series, is in production by Noel Schwerin of [Backbone Media](#). This series will explore the effects of cutting-edge science (such as genetic technology) on the courts and on democratic institutions; people's relationships; and notions of truth, justice, and individual rights.
- For the Spanish-speaking public, the DOE ELSI program supported the broadcast of about 100 Spanish-language radio episodes within a nationally syndicated science and technology [series](#). Molly Multedo and Clay

Dillingham of the [Self Reliance Foundation](#) have led this project.

- [The DNA Files](#), a nationally syndicated series of programs on the social implications of human genome research, was produced by Barinetta Scott and Jude Thilman of SoundVision Productions. Broadcast over National Public Radio stations beginning in November 1998, the series won the prestigious DuPont-Columbia University television and radio award in 2000 and the 2001 Peabody award.
- [A Question of Genes](#), a 2-hour television documentary produced by Noel Schwerin, looked at a series of families and individuals challenged by the outcomes of genetic testing for inherited diseases. Broadcast on the Public Broadcasting System in September 1997, the program received an Emmy nomination. [videotapes, 800/440-2651]
- The National Educational Foundation of the African-American sorority, Zeta Phi Beta, has conducted two workshops for more than 200 people to introduce the fundamentals of the Human Genome Project and some of its potential implications for people of color. The first workshop was held in New Orleans in 1999 and the second ([Challenges of Genome Research for Minority Communities](#)) in Philadelphia in 2000. Zeta Phi Beta is holding a number of follow-up workshops all over the country to inform minority communities about the genome project's ELSI implications.
- In May 1997, DOE supported a meeting organized by Carmen Nieves and Ray Zilinskas of the University of Maryland to inform minority communities about the HGP. The meeting also was designed to acquaint genome project scientists and policymakers with the aspirations and interests of these communities. A new book edited by Zilinskas and Peter Balint (*The Human Genome Project and Minority Communities : Ethical, Social, and Political Dilemmas*, Nov. 2000) builds on insights gained at the conference. [[Human Genome News](#) 9(1-2), 19-20]
- In September 1996, DOE and NIH jointly sponsored a major conference at Tuskegee University on "Plain Talk About the Human Genome Project", which addressed some of the HGP's implications for African Americans. An updated compilation of all the conference talks was published in 1997. [Article in [Human Genome News](#) 8(2), 9-10]; Book: Tuskegee University Publications Office (334/727-8035, Fax: /724-4451]
- As part of a 2-year project beginning in FY 1996, Maria Sosa of the American Association for the Advancement of Science developed and distributed *Your Genes, Your Choices*, a high-interest book and video designed for readers of all ages. The book has been translated into a number of different languages, including Icelandic. [Downloadable from the [Web](#) or order from AAAS (202/326-6454, Fax: /371-9849, croyster@aaas.org)]
- From 1990 to 1995, Michael Yesley of Los Alamos National Laboratory maintained a comprehensive bibliographic [database](#) of ELSI publications related to the genome project. Thousands of books and articles were cataloged, and copies of most materials were archived for the library collection.
- Charles Carlson of the San Francisco Exploratorium and Elizabeth Sharpe of the Smithsonian's Museum of American History each received DOE support in 1995 for exhibits on genetics and the HGP.
- *Medicine at the Crossroads*, a four-part documentary jointly sponsored with NIH, was produced by George Page and Stefan Moore at WNET/Thirteen in New York and shown around the country on public television in the spring of 1993. A book, *Medicine at the Crossroads: The Crisis in Health Care* by Melvin Konner, also resulted from this series. [Set of eight videos: PBS Home Videos (800/328-7271); Book: Vintage Books Reprint edition (1994) available through online booksellers]
- *The Secret of Life*, a WGBH series produced by Paula Apsell and Graham Chedd and narrated by David Suzuki, was shown in the fall of 1993. A set of eight videos was produced from this series. [Set of eight videos: out of print.]
- Jan Witkowski of the Cold Spring Harbor DNA Learning Center conducted several workshops in 1991 and

1992 to inform opinion leaders and public policymakers about genomics and the genome project's implications for society.

- A 3-year DOE and NIH project that began in 1990 sponsored two national conferences on genetics, religion, and ethics. They were organized by C. Thomas Caskey of the Baylor College of Medicine and J. Robert Nelson and Hessel Bouma III of the Texas Medical Center Institute of Religion. This project led to a book by Nelson in 1995 titled *On the New Frontiers of Genetics and Religion*. [Book out of print]
- Miriam Pollack of the North Suburban Library System in Chicago is encouraging genetic literacy by using the public libraries to organize community and scientific experts, gather resources and materials on the HGP, and establish educational activities. The pilot program will be available first in ten Chicago-area libraries and later to others throughout the country.
- A comprehensive and well-organized network of Native-American tribal professionals is focusing on the HGP in a program led by Mervyn Tano of the Institute for Indigenous Resource Management in Denver, Colorado. This project will introduce Native-American tribes to the basics of genetics, genetic research, and the HGP and will, in turn, inform DOE HGP managers about tribal perspectives.

Education for Professional Groups

- Jeroo Kotval of the University of New York at Albany is examining confidentiality concerns raised by the use of DNA-based test results in the managed-care (MCO) setting. This area presents unique ethical dilemmas because the MCO is both payer and provider and because physicians and, quite often, laboratory personnel are MCO employees. [jsk03@health.state.ny.us]
- With a view to making draft recommendations regarding policymaking, Henry Greely and Barbara Koenig at [Stanford University](#) are studying the societal implications of using individual genetic variations for medical decision-making.
- Many disorders associated with mental retardation have genetic roots, with Down syndrome and fragile X syndrome the most common. New genetic findings from the HGP pose unique ethical questions and legal and social concerns to those with disabilities and their families. To address these concerns, in 1998 Sharon Davis of [The Arc of the United States](#) developed and distributed a series of reports, fact sheets, and workshop training packages to all 1100 organization chapters. [sdavis@metronet.com]
- Another Stanford [project](#), by Sara Tobin, is producing an interactive multimedia CD-ROM medical education course for physicians, most of whom have received little or no training in clinical applications of molecular genetics.
- In a series of workshops held since 1994, Franklin Zweig of the [Einstein Institute for Science, Health, and the Courts](#) (EINSHAC) has trained more than 1900 federal and state judges for the expected onslaught of cases involving genetics. In addition, the DOE-supported Summer 1997 issue of *The Judges' Journal of the American Bar Association* was devoted to "Genetics in the Courtroom." [Reprints of certain articles available from HGMIS and on the [Web](#).
- Elizabeth Hodges of the Administrative Office of the Courts in New Hampshire held a conference in October 2000 that introduced 100 judges from Maine, New Hampshire, and Vermont to the basics of genomics and genetics. This training meeting was based on the EINSHAC model, although funded separately.
- Paul Sullins of Catholic University, Washington, D.C., is holding a small training conference for the clergy, who often are counsels of last resort in the resolution of such moral and ethical dilemmas as those surrounding genetic test results. This conference will be modeled on the EINSHAC series for judges.
- In 1995 and 1996, Mary Mahowald of the University of Chicago held a series of workshops, followed by a national conference in the spring of 1997, to help prepare medical doctors and primary caregivers for the

geneticization of healthcare.

- Joseph McInerney's project at the National Coalition for Health Professional Education in Genetics is producing an interactive CD-ROM to instruct genetic counselors about disorders that have at least a partial genetic basis.

Informing Teachers and Students

- *Winding Your Way Through DNA* was a 1992 San Francisco symposium and public forum on molecular biology and its applications for high school teachers and students. Six videos of the symposium were made and distributed. [Set of six videos distributed by Cold Spring Harbor Laboratory Press (800/843-4388) and Pyramid Media (800/421-2304 or 310/828-7577)].
- David Micklos of Cold Spring Harbor Laboratory is leading a nationwide series of [workshops](#) for high school biology teachers. He is introducing a laboratory-based unit on human DNA polymorphisms (genetic differences) and the ELSI aspects of the genome project.
- An innovative [program](#) led by Maureen Munn through the University of Washington, Seattle, allows high school students to perform DNA synthesis and sequencing in the classroom. Munn also conducts workshops at teachers' conferences and meetings around the country. Local teachers, as well as those from other states, have attended week-long summer workshops in Seattle and receive continuing assistance with the experiments through equipment and technical advice after they return home.
- In conjunction with other local and national organizations, Debra Collins of the University of Kansas Medical Center trained over 175 high school science teachers annually as state "resources" in molecular genetics and the latest biotechnology methods. In a "trainer of trainers" model, they in turn prepared thousands of additional teachers, who are reaching a million students. [www.kumc.edu/gec]
- At California State University in Los Angeles, Margaret Jefferson's project translated into Spanish the Biological Sciences Curriculum Study (BSCS) module, *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy*. The module was used by Spanish-speaking students and parents in selected high schools.
- In addition to the module on mapping and sequencing, [BSCS](#) has produced three others for high school teachers and students. One was on genetic database design and the societal effects of accumulating large amounts of information in computer-accessible form. Another module examined nontraditional inheritance mechanisms for genetic information. The most recent module, completed in 2000, covers genes, environment, and human behavior and is being used by many high school biology classes. The BSCS group, now led by Mark Bloom, is working on a new module on bioinformatics and genomics that should be ready in 2002.
- Robert Robbins of the Fred Hutchinson Cancer Research Center established and is maintaining an educational [Web](#) resource to republish classical literature (both papers and monographs) on genetics. This project helps promote a foundation for understanding the new genetics and genome technology.
- Summer workshops held by Sylvia Spengler and the California Community Colleges from 1996 to 1997 at Lawrence Berkeley National Laboratory were designed to upgrade the biotechnology skills of community college students and teachers.
- At Stanford University, a 1996 collaborative effort led by Lane Conn and based in the [Stanford Human Genome Center](#) aimed to develop a national human genome curriculum for high school science and to provide education outreach to schools and community groups in the San Francisco Bay area.
- Jeff Davidson of the Pennsylvania Biotechnology Association (PBA), in cooperation with the Alliance for Science Education, produced the biotechnology magazine *Your World, Our World*, designed for grades 7 through 10. In 1996, PBA published a special enlarged issue dealing with the science of genomics and the ELSI implications of the HGP.

- Two 5-day continuing-education workshops for high school science teachers from the Great Lakes region were held annually at the University of Michigan by Diane Baker and Paula Gregory in 1993 and 1994. The purpose was to instruct science teachers in the latest developments in human genetic research and its ELSI implications.

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Exploring Public Policy Issues

The DOE ELSI program has focused on a broad range of genetic issues from the perspectives of several disciplines, including philosophy, social science, and law. Through grants and commissioned papers, the program has supported studies to consider such factors as the attitudes toward genetic privacy in different populations; the need for appropriate measures to protect genetic information in various contexts, including healthcare and the workplace; and the evolving policies of private institutions and state, federal, and foreign governments. The following projects were designed to increase the growing body of knowledge and to promote informed discourse leading to policy development.

NOTE: See also the previous section on Education for Professional Groups.

Privacy

The fair use of genetic information raises particularly difficult practical, commercial, and philosophical problems related to access and disclosure. Should genetic information be private or shared? With whom? When?

Questions such as these may be closely intertwined with the economics of the U.S. healthcare industry; organizations may claim (with some justification) the right to patient information related to procedures for which they pay (e.g., genetic tests). Since they paid for the results, the argument continues, they can act in their own self interest and not necessarily in that of the patient. The inevitable result is a conflict between the insured and such third parties as insurers, employers, adoption agencies, and educational institutions. These groups may want access to genetic data having predictive or diagnostic value, while those tested may feel that such access could lead to discrimination and decisions based too heavily on genetics.

- In 1993–94 a study by Alan Westin of Columbia University related existing social science work on privacy to anticipated genetic-privacy issues. This project also examined current privacy-protection measures, debates over the need to update privacy protection, and implications for social and legal policies to deal with expected future genetic testing and applications of genetic data.
- To strengthen the dialogue between the professional genetics community and federal policymakers, a congressional fellowship program was initiated in 1995. This program allows genetic professionals to spend a year as special legislative assistants on the staffs of members of Congress or on congressional committees.
- Philip Reilly was a major organizer of two ELSI symposia in 1998 and 2000 at the Whitehead Institute for Biomedical Research. Following each meeting, CD-ROMs containing the syllabus, transcripts of all plenary talks, and links to relevant Web sites were distributed to thousands of people. [Contact Gus Cervini (cervini@wi.mit.edu; 617/258-0633, [HGN articles about the 1998 symposium.](#))]
- Under a grant to the Library of Congress, Philip Kitcher, a philosopher at the University of California, San Diego, researched genome ELSI issues and wrote *The Lives to Come: The Genetic Revolution and Human Possibilities*, a well-received book published by Touchstone Books in 1997. The book explores both the science and the ethical and moral dilemmas arising from the genome project. [Order through online booksellers]
- In a [project](#) jointly sponsored by NIH and DOE, Troy Duster and Diane Beeson of the University of California, Berkeley, conducted a major study between 1992 and 1997. Their goal was to illuminate the processes by which genetic screening and genetic concepts of health and illness are integrated into the health concerns of high-risk families. A series of scholarly papers and book chapters resulted from this study. [Report requests: [Janice](#)

[Tanigawa](#) (510/642-0813)]

- With NIH, DOE supported a study led by Ruth Bulger and Jane Fullarton at the Institute of Medicine to address a variety of issues raised by the rapid proliferation of predictive genetic tests in otherwise healthy individuals. This study led to the 1994 publication of *Assessing Genetic Risks: Implications for Health and Social Policy*, a report with recommendations for the use of genetic information in healthcare. [[website](#)]
- A DOE workshop on "Medical Information and the Right to Privacy," held in June 1994 in Washington, D.C., led to the book *Genetic Secrets: Protecting Privacy and Confidentiality* (1997), edited by Mark Rothstein of the University of Houston. Now reprinted in paperback, the book explores the full range of issues related to genetic privacy. [www.yale.edu/yup]
- In a DOE-commissioned paper, an early philosophical study of privacy by Madison Powers of Georgetown University offered a conceptual foundation, with particular attention to genetic information, for analyzing and resolving issues of genetic privacy.
- A new project, led by Mary Bishop of Virginia Technological Institute and State University, is seeking to preserve the history of the eugenics program conducted in Virginia in the 1920s. She and her colleagues will interview about ten known survivors who were forcibly sterilized, as well as the government officials and others who were instrumental in creating and carrying out the policy.
- To explore connections between workplace exposure and a number of complex genetic disorders, Laura Roberts of the University of New Mexico is conducting interviews with nearly 500 people. Her team seeks to determine the influence of such variables as race, ethnicity, and gender on the development of these disorders.

Privacy Legislation

Focusing on privacy concerns, some proposed legislation has attempted to establish a legal framework of fair practices for health information and to regulate its access, disclosure, and use. Ten years after the formal start of the HGP in 1990, some 30 states have passed various laws addressing genetic privacy, but these laws are not uniform from state to state.

Only a few federal actions have any bearing on genetic privacy. An interpretation of the 1990 Americans with Disabilities Act (ADA) by the Equal Employment Opportunity Commission asserted that ADA covers genetic discrimination in employment, but the finding awaits clarification by the courts. The 1996 Health Insurance Portability and Accountability Act bars the use of genetic information to deny health insurance to people who change jobs; this act, however, does not regulate their new insurance premiums (which, if evidence of a genetic condition exists, may be prohibitively high).

In May 2000, President Clinton issued an Executive Order banning the U.S. government and its agencies and departments from using genetic information in most hiring decisions. This ban does not affect most of the private sector. In December 2000, the president announced sweeping regulations to protect the privacy of medical records. Patients now must give special permission if their records are used for such non-routine purposes as supplying employers with information about job candidates or helping product marketers compile lists of people with specific conditions.

Examples follow of DOE projects relating to the confidentiality of genetic information.

- A draft bill (*Genetic Privacy Act*) was written in 1995 by George Annas of the Boston University School of Public Health to assist legislators. This bill proposed that access to information in genetic data banks should be regulated during sample collection, storage, disclosure, and use. Several state lawmakers adapted language and concepts from the draft bill to write proposals for legislation in their own states. The *Genetic Privacy Act and Commentary* is on the [Web](#).
- In 1994, Reilly and Jean McEwan of the Shriver Center surveyed existing bills and laws with a view to drafting model legislation for protecting the confidentiality of personal genetic information. They found that state

legislative efforts to regulate the use of such data have increased, particularly in employment and insurance, but major gaps and deficiencies in statutory coverage persist.

Family Matters

An individual's genetic information also may pertain to such family members as parents, siblings, and other relatives. DOE ELSI grantees have been studying legal precedents for either protecting or disclosing genetic information among family members, as well as the philosophical and legal basis for intrafamilial obligations. Some examples of these studies are listed below.

- A DOE-commissioned paper by Lori Andrews of the American Bar Foundation explored genetic privacy in the context of familial responsibilities. This paper was developed into a chapter in Rothstein's *Genetic Secrets* book.
- A 1992–94 study by Frank Grad of Columbia University Law School examined the rationale for protecting genetic information. The study considered the balance between an individual's right to confidentiality and the value of disclosure to protect public health and the interests of relatives and intended spouses.

Data Banks

Interest in forensic DNA data banks is growing, with all states except Massachusetts having laws that authorize the collection of samples from convicted felons. Some DOE projects on this subject are highlighted below.

- Two separate DOE studies by Philip Reilly and George Annas focused on the growing practice of banking individuals' DNA or genetic data in forensic, academic, military, and commercial arenas. These studies involved research on privacy in these settings and on developing and refining proposed policies and guidelines. Reilly's project, which reported widespread uncertainty about the types of sample releases that are legally or ethically prohibited, led to the production of a 28-minute video called *Banking Our Genes*. [Video: Fanlight Productions (800/937-4113)]
- Concentrating on Florida and Georgia, Ralph Trottier of the Morehouse School of Medicine and Lee Crandall of the University of Illinois explored differences between state-supported programs for genetic testing, screening, and counseling. Jointly sponsored with NIH, this 1992–94 project particularly addressed the issue of confidentiality in a mobile society of broad ethnic diversity. A [report](#) and a series of published papers were based on this work.

Discrimination

Public meetings, hearings, and publications have indicated that the possibility of discrimination is one of the principal fears associated with the wider availability of genetic information. Examples follow of DOE-supported research to assess the significance of genetic discrimination in such settings as schools and workplaces.

- From 1997 to 1998, Mark Rothstein examined the effects of a unique Minnesota law that limited access to employee medical records to job-related matters, with a view to making the law a model for protecting genetic privacy in the workplace. He found that the Minnesota law had little effect because people were not aware of it. [mrothstein@uh.edu]
- A 1992–94 empirical study by Carol Barash and Marvin Natowicz of the Shriver Center examined genetic discrimination experienced by individuals in dealing with such social institutions as employers, insurers, and schools. These studies indicated a need to protect against certain disclosures and uses of genetic information.
- A survey by Philip Reilly showed that life insurance companies are more interested in obtaining existing genetic test information than in performing tests on applicants. Company ratings based on genetic conditions reflect a considerable degree of subjectivity rather than actuarial data.
- Lynn Pasquerella and Lawrence Rothstein of the University of Rhode Island are studying the laws and legislative proposals of ten eastern states and the federal government regarding the use of genetic information in the workplace. The investigators will try to determine the ethical concepts used and how these concepts influenced policy development that resulted in legislation. One outcome of the project will be a partial

assessment of the influence of ELSI research over the past decade.

Patents

Massive amounts of data flowing from the Human Genome Project and other genomics projects have stimulated an avalanche of applications for patents on genes and gene fragments. This situation has sparked controversy among scientists, many of whom feel that broad patents should not be granted at this early stage to applicants who have neither characterized the genes nor determined their functions and specific uses.

The other side of this debate is rooted in the traditional view of many in the private sector that patents are necessary to promote the commercialization of new discoveries in the form of useful inventions. Ultimately the U.S. Patent and Trademark Office, as reviewed by the courts (and possibly Congress), must resolve these issues. What the ELSI program can do is clarify the issues and explore the ramifications of various options surrounding the release of genomic data.

Two DOE projects on this topic are listed below.

- At the University of Michigan Law School, an ongoing project started in 1996 by Rebecca Eisenberg has explored the role of patents in transferring technology generated by the genome project to society at large. Eisenberg also is conducting a study with Michael Heller on the trend toward privatization and patenting of the early stages of biomedical and microbial genome research. A series of influential publications has resulted from this work.
- In a project based in part on Eisenberg's studies, David Bjornstad of Oak Ridge National Laboratory is carrying out an economic analysis of intellectual property rights related to the HGP. He and his colleagues are employing experimental economics to examine the influence of various strategies used to commercialize the fruits of the HGP.

Institutional Review Boards

Institutional review boards (IRBs) are responsible for overseeing procedures at such institutions as hospitals and research facilities, particularly protocols that might affect the rights and welfare of human research subjects. Increasingly complex ethical, regulatory, and scientific issues are proving challenging to these boards, which often are composed largely of nongenetic professionals. Examples of DOE studies addressing this issue follow.

- To assist IRBs in reviewing genomic protocols, especially those involving human subjects and tissues, Barbara Handelin's [project](#) at Public Responsibility in Medicine and Research is focusing on educating IRBs in the special language, technologies, and issues that typify these protocols.
- Although not an HGP ELSI project, the related DOE [program](#) on Protecting Human Subjects is designed to safeguard the rights and welfare of human research subjects.

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Conclusion

Our genomes come from our parents, and we cannot choose them. The genes we acquire at conception stay with us, largely unchanged, all our lives. At this time (although this may be different in the future), we can do nothing to alter our genes. Many mysteries remain about how our genes work, how (and when) they are expressed, and how our environments or chance acts on them. Even with the human genome sequence nearly completed, we are a long way from understanding how we turn out the way we do.

Identical twins, who begin life with identical genomes and therefore are more similar than fraternal siblings, nonetheless are distinct individuals with different personalities, behaviors, disease susceptibilities, abilities, and life histories. This shows that our genetic makeup can explain only so much, not everything, about us. Such limits to the influence of genetics sometimes are overlooked in the enthusiasm for possible outcomes generated by the recent

extraordinary progress in genome research.

Still, the simple continuing importance of ELSI studies is that each person has a unique genome that both identifies the individual and has predictive implications for future health. An "ideal" or "perfect" genome does not exist, even if such a concept could be defined. All genomes contain small variations that could severely and adversely affect health under differing circumstances or if they were not influenced or masked by other genes; this information about the individual has value to other people and groups who may have their own agendas. Thus, while the HGP's potential benefits are enormous for medicine, bioremediation, agriculture, and many other socially and economically important areas, we must remain alert to its more problematic implications as well.

As the project moves closer to its goal of obtaining the complete human reference DNA sequence by 2003, society will face questions surrounding variations in individual sequences, uncertainties regarding their significance for health and longevity, and the implications of knowing about these subtle distinctions before their biological effects are understood. Although many ELSI issues are not limited to the genome project, they nonetheless remain challenging and need to be addressed. Only by dealing directly and openly with such considerations through the collective best efforts of bioethicists, scientists, policymakers, and the public can the benefits of genome research be realized and the difficulties minimized. Just as genome scientists need to become active participants in the discussion of these difficult issues, so too must the "ELSI scholars" learn the relevant genetic science so the very important dialogues remain firmly grounded in scientific reality. The "genome-enabled" future is extraordinarily exciting and promising for dramatic improvements in health, medicine, and biological understanding, but it is not without its perils. To address them and to improve the likelihood that we collectively introduce these benefits in the best way to the greatest number of people will take much wisdom as well as our best efforts for many years to come.

Information Sources

Many of the documents mentioned in this article and abstracts of all past and current DOE ELSI projects are available on the [Web](#). The site also contains the ELSI goals in the latest HGP 5-year plan; societal concerns arising from the new genetics; articles and discussions on genetic privacy and discrimination, patenting, gene testing, gene therapy, behavioral genetics, and genetics in the courtroom; and extensive links to other Web sites.

For corrections or further information, contact Human Genome Management Information System; Oak Ridge National Laboratory; 1060 Commerce Park; Oak Ridge, TN 37830 (865/574-9851, Fax: /574-9888).

Grants in the DOE Ethical, Legal, and Social Issues Program (1990 to 2001)

[List compiled August 2001 by Daniel Drell, manager of the ELSI component of the DOE Human Genome Program, and Anne Adamson, Human Genome Management Information System (HGMIS).]

ELSI projects sponsored by the DOE Human Genome Program between 1990 and 2001 are listed below with principal investigators, award dates, and resulting products. HGMIS is aware that the list of products is incomplete for some projects, and this is only a partial list of conferences. To find a particular grantee or topic, search using the "Find in Page" function under your browser's "Edit" pulldown menu.

Title: *The Secret of Life*

P.I.: Paula Apsell, WGBH Educational Foundation

Project Period: 6/01/90 to 12/31/93

Products:

Television series consisting of eight 1-hour documentaries shown on PBS in 1993.

Set of eight videocassettes.

J. Levine and D. Suzuki, *The Secret of Life: Redesigning the Living World*, WGBH Educational Foundation, Boston, 280 pp. (1993).

Title: Assistance for Ethical, Legal, and Social Issues Program and ELSI Bibliography

P.I.: Michael Yesley, Los Alamos National Laboratory

Project Period: 10/01/90 to 9/30/96

Products:

Bibliography on Web: https://public.ornl.gov/site/external/elsi_search.cfm

Michael Yesley, *Bibliography: Ethical Legal and Social Implications of the Human Genome Project*, U.S. Department of Energy, Office of Energy Research (1992).

Michael Yesley, *ELSI Bibliography: Ethical Legal and Social Implications of the Human Genome Project*, U.S. Department of Energy, Office of Energy Research (1993).

Michael Yesley, *ELSI Bibliography: Ethical Legal and Social Implications of the Human Genome Project: Supplement*, U.S. Department of Energy, Office of Energy Research (1994).

M. S. Yesley, "Genetic Privacy, Discrimination, and Social Policy: Challenges and Dilemmas," *Microb. Comp. Genom.* **2**(1), 19-35 (1997).

Title: Predicting Future Disease: Issues in the Development, Application, and Use of Tests for Genetic Disorders

P.I.: Ruth Bulger, National Academy of Sciences

Project Period: 2/08/91 to 7/31/93

Products:

Lori B. Andrews et al., eds., *Assessing Genetic Risks*, National Academy Press, Washington, D.C. (1994).

Lori B. Andrews, "Gen-Etiquette: Are There Moral and Legal Responsibilities to Share Genetic Information Within Families?" Chapter 14 in *Genetic Secrets, Protecting Privacy and Confidentiality in the Genetic Era*, ed. Mark Rothstein, Yale University Press, New Haven and London (1997).

Title: Conference on Legal and Ethical Issues Raised by the Human Genome Project, held March 7-9, 1991

P.I.: Mark Rothstein

Project Period:

Products:

Health Law Issue, "Symposium: Legal and Ethical Issues Raised by the Human Genome Project," *U. Houston Law Rev.* **29**(1), Spring 1992.

Title: Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy Development and Distribution of Educational Materials for Use in High School Biology Classes

P.I.: Joseph McInerney, Biological Sciences Curriculum Study

Project Period: 3/10/91 to 3/09/93

Products:

Joseph McInerney et al., *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy*, Biological

Sciences Curriculum Study, Colorado Springs, Colorado (1992).

J. D. McInerney, "Molecular Biology: How Can We Translate the Laboratory?" in *Genes and Human Self-Knowledge*, ed. R. F. Weir, S. C. Lawrence, and E. Fales, University of Iowa Press (1994).

J. D. McInerney, "The Human Genome Project's Relevance to Genetics Education in High Schools," *Am. J. Human Genet.* 52 (1), 235-38 (1993).

J. D. McInerney, "The Human Genome Project and Biology Education," *BioSci.* 45(11), 786-91 (1995).

J. D. McInerney, "Why Biological Literacy Matters: A Review of Commentaries Related to *The Bell Curve: Intelligence and Class Structure in American Life*," *Q. Rev. Biol.* 71(1), 81-96 (1996).

Title: Human Genetics for Nonscientists: Practical Workshops for Policymakers and Opinion Leaders

P.I.: Jan Witkowski, Cold Spring Harbor Laboratory

Project Period: 3/15/91 to 12/31/95

Two residential workshops held yearly for 3 years.

Title: Conference on Justice and the Human Genome, held November 1991

P.I.: Mark Lappé, University of Illinois

Project Period: 3/15/91 to 3/14/92

Products:

Timothy Murphy and Mark Lappé, eds., *Justice and the Human Genome Project*, University of California Press (1994).

Title: Funding of Young Investigators in the Biological and Biomedical Sciences

P.I.: Eric Fischer, National Academy of Sciences

Project Period: 5/1/91 to 7/31/92

Products:

National Research Council, *The Funding of Young Investigators in the Biological and Biomedical Sciences*, 128 pp., 1994.

Title: National Study Conference on Genetics, Religion, and Ethics

P.I.: C. Thomas Caskey, Baylor College of Medicine

Project Period: 7/01/91 to 6/30/93

Products:

Two national conferences held in 1991 and 1992.

"Summary Reflection Statement," *Hum. Gene Ther.* 3(5), 525-27 (October 1992).

J. Robert Nelson, *On the New Frontiers of Genetics and Religion*, Eerdmans Publishing, Grand Rapids, Michigan (1995).

Title: Genetic Privacy: A Search for Model Legislation

P.I.: Philip R. Reilly, Shriver Center

Project Period: 9/01/91 to 2/28/93

Products:

J. E. McEwen and P. R. Reilly, "Genetic Testing and Screening-VI, Legal Issues," pp. 943-49 in *Encycl. Bioeth.*, Vol. 2, ed. W. Reich, Simon & Schuster MacMillan (1994).

P. R. Reilly, "Genetics and the Law," pp. 967-77 in *Encycl. Bioeth.*, Vol. 2, ed. W. Reich, Simon & Schuster MacMillan, New York (1994).

J. E. McEwen, K. McCarty, and P. R. Reilly, "A Survey of Medical Directors of Life Insurance Companies Concerning Use of Genetic Information," *Am. J. Hum. Genet.* **53**, 33-45 (1993).

J. E. McEwen, K. McCarty, and P. R. Reilly, "A Survey of State Insurance Commissioners Concerning Genetic Testing and Life Insurance," *Am. J. Hum. Genet.* **51**, 785-92 (1992).

J. E. McEwen and P. R. Reilly, "State Legislative Efforts to Regulate Use and Potential Misuse of Genetic Information," *Am. J. Hum. Genet.* **51**, 637-47 (1992).

Title: Workshop on DNA Sequence Acquisition and Interpretation, held October 1991

P.I.: Jan Witkowski, Cold Spring Harbor Laboratory

Project Period: 9/10/91 to 9/19/92

Title: *Medicine at the Crossroads*

P.I.: Hyman H. Field, National Science Foundation

Project Period: 9/16/91 to 9/15/94

Products:

Four-part documentary series shown on public television in 1993.

Set of eight videocassettes (1993).

Melvin Konner, *Medicine at the Crossroads: The Crisis in Health Care*, Vintage Books (Reprint Edition, 1994).

Title: Science and Journalism Conference III, Genes and Human Behavior: A New Era? held October 1991

P.I.: Jonathan Beckwith, Center for Study of Public Policy

Project Period: 10/22/91 to 10/15/92

Products:

P. R. Billings, J. Beckwith, and J. S. Alper, "The Genetic Analysis of Human Behavior: A New Era?" *Soc. Sci. Med.* **35**(3), 227-38 (1992).

J. Beckwith and J. S. Alper, "Human Behavioral Genetics," *Genet. Resour.* **10**(2), 5-9 (1996).

J. S. Alper and J. Beckwith, "Genetic Fatalism and Social Policy: The Implications of Behavior Genetics Research," *Yale J. Biol. Med.* **66**(6), 511-24 (Nov.-Dec. 1993).

Title: Committee on Biotechnology

P.I.: Oskar Zaborsky, National Academy of Sciences

Project Period: 2/01/92 to 1/31/95

Title: Second Conference on Computers, Freedom, and Privacy, held March 1992

P.I.: Lance Hoffman, George Washington University

Project Period: 2/15/92 to 2/14/93

L. Hoffman, ed., *Proceedings of the Second Conference on Computers, Freedom, and Privacy* (1993).

Title: Week-Long Educational Forum Focusing on Science, Technology, and Ethical Responsibility, held June 1992

P.I.: Betsy Fader, Student Pugwash USA
Project Period: 3/01/92 to 2/28/93

Products:

B. Fader, "Visions for A Sustainable World: Science, Technology, and Social Responsibility," Conference Report (June 1992).

B. Fader, "Ethics and the Use of Genetic Information—Tough Questions by Student Pugwash USA," Conference Report, 7–11 (Summer 1992).

Title: Lawful Uses of Knowledge from the Human Genome Project

P.I.: Frank Grad, Columbia University
Project Period: 3/15/92 to 3/14/94

Products:

Frank Grad and I. L. Feitshans, *The Lawful Uses of Knowledge from the Human Genome Project* (1992), unpublished.

Title: Human Genome Teacher Networking Project

P.I.: Debra Collins, University of Kansas
Project Period: 3/31/92 to 3/31/98

Products:

Web Site: <http://www.kumc.edu/gec>

Through the networking system established under this grant, Debra Collins presented numerous workshops and teacher participants trained many others through workshops, courses, and sharing of educational materials.

D. L. Collins, J. Bailey-Wilson, and M. S. Boguski, "User-Friendly Access to Computer Information," Workshop at the American Society of Human Genetics Meeting, October 1995 in Minneapolis, Minnesota.

D. L. Collins, J. Shaw, and K. Dietrich, "On-Ramp to the Information Superhighway: How the Internet can Aid the Genetic Counselor," National Society of Genetic counselors, Minneapolis, Minnesota, October 1995.

D. L. Collins, "Medical Genetics Information on the Internet: Three Years Experience," Platform Presentation at the American Society of Human Genetics Annual Meeting, October 1997 in Baltimore, Maryland.

D. L. Collins, B. Fine, and D. L. Baker, "Introduction to Proposal Writing for Grants," Three-Hour Workshop at the National Society of Genetic Counselors Meeting, October 1997 in Baltimore, Maryland.

D. L. Collins, "Teachers and Students Benefit from Human Genome," Workshops at American Society of Human Genetics Meeting, October 1998 in Denver, Colorado.

Title: Studies of Genetic Discrimination

P.I.: Marvin Natowicz, Shriver Center
Project Period: 4/01/92 to 2/28/94

Products:

J. S. Alper and M. R. Natowicz, "Genetic Discrimination and the Public Entities and Public Accommodations Titles of the Americans with Disabilities Act," *Am. J. Human Genet.* **53**, 26-32 (1993).

- J. S. Alper, M. R. Natowicz, and C. F. Ard, "Discrimination on the Basis of Perceived Genetic Disabilities," *Disabil. Stud. Q.* **13**, 27-30 (1993).
- J. S. Alper et al., "Genetic Discrimination and Screening for Hemochromatosis," *J. Pub. Health Pol.* **15**, 345-58 (1994).
- P. R. Billings et al., "Discrimination as a Consequence of Genetic Testing," *Am. J. Hum. Genet.* **50**, 472-82 (1992).
- L. N. Geller et al., "Individual, Family, and Societal Dimensions of Genetic Discrimination: Case History Analyses," *Sci. Engr. Ethics* **2**, 71-88 (1996).
- M. R. Natowicz, J. K. Alper, and J. S. Alper, "Genetic Discrimination and the Law," *Am. J. Hum. Genet.* **50**, 465-75 (1992).

Title: Impact of Human Genome Initiative-Derived Technology on Genetic Testing, Screening, and Counseling: Cultural, Ethical, and Legal Issues

P.I.: Ralph Trottier, Morehouse School of Medicine

Project Period: 5/01/92 to 12/30/94

Products:

Eight symposium presentations.

Ralph Trottier and Lee Crandall, *Public Sector Genetic Services: Current Status and Potential Issues Raised by the Human Genome Project* (1996), unpublished report.

D. A. Phoenix et al., "Sickle Cell Screening Policies as Portent: How Will the Human Genome Project Affect Public-Sector Genetic Services?" *J. Nat. Med. Assoc.* **87**, 807-12 (November 1995).

L. A. Crandall, "Genetic Testing and Managed Care: Balancing Individual, Family, and Corporate Interests" in *Resources, Rationing, and Responsibility: Ethical Issues in Managed Care* (Continuing Education Conference Papers), Indiana University School of Medicine, Division of Continuing Education, Indianapolis (1996).

S. V. McCrary and W.L. Allen, "The Human Genome Initiative and Primary Care" in *Ethics: Critical Issues for Today's Health Professional*, ed. J.F. Monagle and D.C. Thomama, Aspen Publishers, Gaithersburg, Maryland, 447 pp. (1994).

R. W. Trottier, "Genetics In Public Health: Implications of Genetic Screening/Counseling in Rural/Culturally Diverse Populations," Chapter 13 in *Technoscience and Cyberculture*, ed. S. Aronowitz, B. Martinsons, and M. Menser, Routledge Press, New York (1996).

D. C. S. James et al., "Professional Preparation of Individuals Who Provide Genetic Counseling Services," *J. Genet. Couns.* **4**, 49-63 (1995).

D. C. S. James et al., "Roles of Physicians, Genetic Counselors, and Nurses in the Genetic Counseling Process," *J. Fla. Med. Assoc.* **82**(5), 403-10 (1995).

S. V. McCrary et al., "Ethical and Practical Implications of the Human Genome Initiative for Family Medicine," *Arch. Fam. Med.* **2**, 1158-63 (November 1993).

R. Moseley et al., "Policy Recommendations for Genetic Testing," pp. 22-23 and 27-28 in *The Female Patient* (August 1993).

L.A. Crandall, "Biomedical Ethics: Challenges from New Technologies" in *Building Bridges: Strategies for the Future*, Proceedings of the 14th Annual Meeting of the Society for Healthcare Planning and Marketing, American Hospital Association, Chicago (1992).

M.A. Dewar et al., "Genetic Screening by Insurance Carriers," Letter in *J. Am. Med. Assoc.* **267**(9), 1207-8 (March 4, 1992).

L. A. Crandall and R. E. Moseley, "Public Policy Implications of Scientific Research: The Human Genome Initiative and the Future of Insurance," Editorial Forum in *N. Biol.* **3**(12), 1135–36 (December 1991).

R. E. Moseley et al., "Ethical Considerations of a Complete Human Genome Map for Insurance," *Bus. Prof. Ethics J.* **10**(4), 69–82 (Winter 1991).

H. Ostrer et al., "Insurance and Genetic Testing: Where are We Now?" *Am. J. Hum. Genet.* **52**(3), 565–77 (March 1993).

Title: Pathways to Genetic Screening: Patient Knowledges-Patient Practices

P.I.: Troy Duster, University of California, Berkeley

Project Period: 5/01/92 to 10/31/97

Products:

Troy Duster and Diane Beeson, *Pathways and Barriers to Genetic Testing and Screening: Molecular Genetics Meets the High-Risk Family* (1997), on [Web](#).

R. C. Yamashita, "Bringing Disease Back In: Provisional Models and Implications for Future Research," *Sociol. Health Care* 14 (1997).

Diane Beeson and Teresa Doksum, "Family Values and Resistance to Genetic Testing," Chap. 9 in *Bioethics in Context*, ed. Barry Hoffmaster, Temple University Press (2001).

Renee Anspach and Diane Beeson, "Emotions in Medical and Moral Life," Chap. 5 in *Bioethics in Context*, ed. Barry Hoffmaster, Temple University Press (2001).

Diane Beeson and Troy Duster, "African-American Perspectives on Genetic Testing," in *The Double-Edged Helix*, ed. Peter Conrad and Jon Beckwith, Johns Hopkins University Press, forthcoming in 2001.

Title: Human Genetic Diversity

P.I.: Mark Weiss, National Science Foundation

Project Period: 8/01/92 to 7/31/93

Title: Pilot Resident Fellow Program in Science and Technology: Bioethics Issues in Molecular Genetics

P.I.: Declan Murphy, Library of Congress

Project Period: 8/15/92 to 8/30/94

Products:

Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities*, Touchstone Books (1997).

Title: Genome Technology and Its Implications: Hands-On Workshops for Educators

P.I.: Diane Baker

Project Period: 4/01/93 to 3/31/96

Products:

Two 5-day continuing-education workshops conducted annually for high school science teachers.

Title: DNA Banking and DNA Databanking: Ethical and Public Policy Issues

P.I.: Philip Reilly, Shriver Center
Project Period: 4/01/93 to 3/31/96

Products:

Banking Our Genes, videocassette (1995).

J. E. McEwen and P. R. Reilly, "Setting Standards for DNA Banks: Toward a Model Code of Conduct," *Microb. Comp. Genomics* **1**(3), 165-77 (1996).

J. E. McEwen and P. R. Reilly, "A Survey of DNA Diagnostic Laboratories Regarding DNA Banking," *Am. J. Hum. Genet.* **56**, 1477-86 (1995).

J. E. McEwen and P. R. Reilly, "A Review of State Legislation on DNA Forensic Databanking," *Am. J. Hum. Genet.* **54**, 941-58 (1994).

J. E. McEwen and P. R. Reilly, "A Survey of State Crime Laboratories Regarding DNA Forensic Databanking," *Am. J. Hum. Genet.* (1994).

J. E. McEwen and P. R. Reilly, "Stored Guthrie Cards as DNA 'Banks'," *Am. J. Hum. Genet.* **55**, 196-200 (1994).

Title: The Human Genome: Science and the Social Consequences. Interactive Exhibits and Programs on Genetics and the Human Genome

P.I.: Charles Carlson, Exploratorium

Project Period: 4/01/93 to 4/30/96

Products:

"[Diving Into the Gene Pool](#)" display and lecture series at the Exploratorium, April-September 1995. Visited by more than 300,000 people. Project resulted in 26 permanent interactive exhibits at the Exploratorium.

Title: Teaching Ethics in the Biomedical and Biological Sciences: A Workshop for Research Faculty, held June 1993

P.I.: Edward Golub, Pacific Center for Ethics

Project Period: 4/01/93 to 9/30/93

Title: Workshop on Between Design and Choice: The Social Shaping of Genetic and Reproductive Technologies, held April 1993

P.I.: Sheila Jasanoff, Cornell University

Project Period: 4/01/93 to 3/31/94

Products:

Adele E. Clarke, "Modernity, Postmodernity, and Reproductive Processes, c. 1890-1900, or 'Mommy, Where Do Cyborgs Come From Anyway?'" in *The Cyborg Handbook*, ed. C. Gray, S. Mentor, and H. Figueroa-Sarriera, Routledge Press, New York (1995).

Charis Cussins, "Reproducing Reproduction: Techniques of Normalization and Naturalization in an Infertility Clinic," in *Reproducing Reproduction*, ed. S. Franklin and H. Ragone, University of Pennsylvania Press, Philadelphia (1997).

Nellie Oudshoorn, "The Transformation of Sex Hormones into the Pill" in *Beyond the Natural Body: An Archaeology of Sex Hormones*, ed. N. Oudshoorn, Routledge Press, London (1994).

Joan Rothschild, "Engineering the 'Perfect Child': Feminist Responses" in *Against Patriarchal Thinking*, ed. Maja Pellkiaan-Engel, VU University Press, Amsterdam (1992).

Charis Cussins, "Les Cycles de la Conception: les techniques de normalisation dans un centre de traitement de la St, rilit,," in *Technol. Culture* **25-26**, 307-38.

Michael Mulkay, "Frankenstein and the Debate Over Embryo Research," *Sci. Technol. Hum. Values* **21**(2), 157-76.

Title: Genetics Adjudication Resource Project

P.I.: Franklin M. Zweig, Einstein Institute for Science

Project Period: 4/01/93 to 4/30/02

Products:

Website: <http://www.einshac.org>

Einshac News online magazine (<http://www.einshac.org>)

Franklin Zweig, "Biomarkers in the Courtroom," pp. 401-21 in *Biomarkers Science and Technology*, ed. M. Mendelsohn, L. Mohr, and J. Peeters, National Academy Press, Washington, D. C. (1998).

Franklin Zweig and Shana Malinowski, *The Biology of Conduct: Judges' Handbook on the Science and Law of Neuro and Behavioral Genetics*, Einstein Institute for Science, Health, and the Courts (2000).

Franklin Zweig, Joseph T. Walsh, and Daniel M. Freeman, "Courts and the Challenges of Adjudicating Genetic Testing's Secrets," Chapter 18 in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, ed. Mark Rothstein, Yale University Press, New Haven and London (1997).

F. Zweig, Review of A. Buchanan et al., "Chance to Choice: Genetics and Justice," in *Amer. Sci.*, in press (February 2001).

F. Zweig, A. Davis, and R. P. Guy, "Legal Scenarios for Life Technologies Cases," *Commun. Genet.*, in press (February 2001).

Franklin Zweig, "Judging Molecular Biology of Murder, Addictive Disorders, and Dementia," *Hum. Genome News* 11(1-2), 14-16 (Nov. 2000).

Franklin Zweig and Diane E. Cowdrey, "Educating Judges for Adjudication of New Life Technologies," *Judicature* 83(3), 157-61 (Nov.-Dec. 1999).

Franklin M. Zweig, "The End of Natural History and the Beginning of Engineered Evolution in the Courts," *Judges' J.* 36(3), 26-30 (Summer 1997).

Franklin M. Zweig, Joseph T. Walsh, and Daniel M. Freeman, "Adjudicating Neurogenetics at the Crossroads: Privacy, Adoption, and the Death Sentence," *Judges' J.* 36(3), 52-58 (Summer 1997).

Representative Meetings and Workshops

- Forging a Genetics Agenda for the Nation's Judicial Branch, Orleans, MA, July 1995
- National Capital Area, Airlie, Va., May 1997
- New England Regional, Orleans, Mass., June 1997
- Chicago Regional, Chicago, Ill., June 1998
- Interregional Training, Orleans, Mass., June 1998
- Genetic Property, Orleans, Mass., August 1998
- Advanced Genetics in the Courtroom, Orleans, Mass., August 1998
- Pacific Northwest Judicial, Seattle, Wash., August 1998
- Mountain West/Great Basin, Snowbird, Ut., October 1998
- Mid-Atlantic, Ocean City, Md., October 1998
- National Neurobehavioral Genetics in the Courtroom, Airlie, Va., June 1999
- California Regional, Berkeley, Calif., July 1999
- Arizona/Southwest Regional, Phoenix, Ariz., November 1999
- Southeast Regional, Asheville, N.C., May 2000

Thailand Planning Group, December 2000

- Chief State Justices, January 2001
- Science Congress of India, January 2001
- California State and Federal, October 2001
- Leadership Conference, Judges and Legislators, November 2001

Title: Social Science Concepts and Studies of Privacy: A Comprehensive Inventory and Analysis for Use in Consideration of Privacy, Confidentiality, and Access Issues

P.I.: Alan Westin, Center for Social and Legal Research

Project Period: 4/01/93 to 3/31/95

Products:

Alan Westin, *Social Science, Policy, and the Uses of Genetic Information* (working title), publication expected in 2002.

Title: Information Management, Access, and Regulation: Educational Materials for High School Biology

P.I.: Joseph McInerney, Biological Sciences Curriculum Study

Project Period: 4/01/93 to 12/31/95

Products:

Joseph McInerney et al., *The Human Genome Project: Biology, Computers, and Privacy*, Biological Sciences Curriculum Study, Colorado Springs, Colorado (1996). Teaching module.

Title: Maximizing the Return from Genome Research: A Conference Concerning the Effect of Patent Scope on Commercial Incentives, held May 1993

P.I.: Thomas G. Field, Jr., Franklin Pierce Law Center

Project Period: 4/15/93 to 10/14/93

Products:

Conference Proceedings, *RISK: Health, Safety, & Environment* 5(2), 1994.

Title: Guidelines for Protecting Privacy of Information Stored in Genetic Data Banks

P.I.: George Annas, Boston University

Project Period: 6/01/93 to 1/31/96

Products:

George J. Annas, Leonard H. Glantz, and Patricia A. Roche, *The Genetic Privacy Act and Commentary* (1995). [On Web at <http://www.ornl.gov/hgmis/resource/privacy/privacy1.html>] Some 650 copies printed and distributed in 1995.

G. J. Annas, L.H. Glantz, and P. A. Roche, "Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations," *J. Law Med. Ethics* 23, 360-66 (1995).

P. A. Roche, L. H. Glantz, and G. J. Annas, "The Genetic Privacy Act: A Proposal for National Legislation," *Jurimetrics* 37, 1-11 (1996).

P.R. Reilly, "The Impact of the Genetic Privacy Act on Medicine," *J. Law Med. Ethics* 23(4), 378-81 (1995).

Title: Planning Process for HUGO International Yearbook (GELS)

P.I.: Alexander Capron, University of Southern California

Project Period: 8/15/93 to 7/31/95

Title: Estimating Gene Frequencies in DNA Forensic Typing

P.I.: Eric Fischer, National Academy of Sciences

Project Period: 1/15/94 to 7/31/96

Title: Discussion Meeting: Human Population Genetics with Special Reference to DNA Sample Matches and Forensic DNA Typing

P.I.: Jan Witkowski, Cold Spring Harbor Laboratory

Project Period: 2/07/94 to 1/31/95

Title: High School Students as Partners in Sequencing the Human Genome

P.I.: Maureen Munn, Kristi Sanford, and Leroy Hood, University of Washington, Seattle

Project Period: 3/01/94 to 12/31/99

Products:

Web site: <http://hshgp.genome.washington.edu>

Online Teaching Modules and Student Activities: DNA Sequencing Module (1998), Ethics Module (1998), DNA Synthesis (1997), and the Virtual DNA Sequencing Unit.

Maureen Munn et al., "The Involvement of Genome Researchers in Partnerships for Genomics Education," *Genome Res.* **9**, 597-607 (1999).

Title: Mechanical Interactive Exhibits on Biotechnology for Science in American Life Exhibition

P.I.: Elizabeth Sharpe, Smithsonian Institution

Project Period: 3/04/94 to 2/28/95

Products: Exhibits on biotechnology.

Title: A Hispanic Educational Program for Scientific, Ethical, Legal, and Social Aspects of the Human Genome Project

P.I.: Margaret Jefferson and Mary Ann Sesma, California State University, Los Angeles

Project Period: 3/15/94 to 9/15/98

Products:

Web Site: <http://caldera.calstatela.edu/hgp>

Curricula designed for students and parents. Student curriculum consists of already available and newly developed materials and activities such as supplemental information in four major units of biology, student-developed surveys, and more. Parent curriculum consists of newsletters written by students in both English and Spanish.

- Unit I--Career Ladders and Opportunities in Genetics
- Unit II-- Family Education: Annual conference for parents, teachers, and students held at California State University, Los Angeles.

Parent focus groups with translators meet regularly at each participating school.

Title: Symposium, The Human Genome: Some Assembly Required. The Methods, Goals, and Implications of the Human Genome Project, held April 1994

P.I.: Gary Stormo, University of Colorado

Project Period: 4/01/94 to 3/31/95

Products:

Booklet of abstracts from conference.

Title: Private Appropriation, Public Dissemination, and Commercial Product Development in Genomics

P.I.: Rebecca Eisenberg, University of Michigan

Project Period: 6/01/94 to 12/31/00

Products:

R. Eisenberg, "Genomic Patent and Product Development Incentives" in *Human DNA: Law and Policy*, ed. B. M. Knoppers, C. M. Laberge, and M. Hirtle, Kluwer Academic Publishers, Netherlands (1997).

R. Eisenberg, "Do EST Patents Matter?" *Trends Genet.* **14**, 379 (1998).

R. Eisenberg, "Structure and Function in Gene Patenting," *Nat. Genet.* **15**, 125 (1997).

R. Eisenberg, "Intellectual Property Issues in Genomics," *Trends Biotechnol.* **14**, 302 (1996).

R. Eisenberg, "Intellectual Property at the Public-Private Divide: The Case of Large-Scale cDNA Sequencing," *Univ. Chi. L.S. Roundtable* **3**, 557 (1996).

R. Eisenberg, "Public Research and Private Development: Patents and Technology Transfer in Government-Sponsored Research," *Va. L. Rev.* **82**, 1663 (1996).

R. Eisenberg and M. Heller, "Can Patents Deter Innovation? The Anticommons in Biomedical Research," *Science* **280**(5364), 698 (1998).

R.S. Eisenberg, "Streamlining the Transfer of Research Tools," *Acad. Med.* **74**(6), 683–85 (1999).

K. Finneran et al., "The Politics of Genetic Testing," *Issues Sci. Technol.* **13**(1), 48–54 (1996).

Title: Conference on Seeking Common Ground: A Forum for People with Disabilities and Genetic Professionals, held November 1994

P.I.: Marsha Saxton, Project on Women and Disability

Project Period: 8/01/94 to 7/31/96

Title: Distinguished Speakers, Genomic Science Series

P.I.: J. Craig Venter, The Institute for Genomic Research

Project Period: 8/15/94 to 8/14/99

Products:

Four annual addresses by distinguished speakers.

Title: Conference on Genetics, Criminal Justice, and the Minority Community: An Introduction for Professionals in Criminal Justice, held September 1994

P.I.: Robert D. Croatti, Northeastern University

Project Period: 9/01/94 to 8/31/96

Title: Which Scientist Do You Believe? Process Alternatives in Technological Controversies conference, held October 1994

P.I.: Thomas G. Field, Jr., Franklin Pierce Law Center

Project Period: 9/01/94 to 8/31/95

Products:

Conference led to the formation of the Risk Assessment and Policy Association (RAPA).

Conference Proceedings, *RISK: Health, Safety & Environment* **6**(2), 1996.

Title: Global Issues Project: Science and Technology for the 21st Century. Meeting the Needs of the Global

Community

P.I.: Betsy Fader, Student Pugwash

Project Period: 9/01/94 to 6/30/95

Title: Forums on Biotechnology

P.I.: Paul Gilman and Eric Fischer, National Academy of Science

Project Period: 9/01/94 to 8/31/00

Products:

Four forums on biotechnology held during grant period to foster open communication in biotechnology research, development, commercialization, and use:

- Intellectual Property Rights and Plant Biotechnology (1996)
- Privacy Issues in Biomedical and Clinical Research (1998)
- Designing an Agricultural Genome Program (1998)
- Bioinformatics: Converting Data to Knowledge (2000)

Intellectual Property Rights and Plant Biotechnology: Proceedings of a Forum Held at the National Academy of Sciences, November 5, 1996, Washington, D.C., National Research Council, National Academy Press, 46 pp. (1997). [On [Web](#)]

Board on Biology, National Research Council, Privacy Issues in Biomedical and Clinical Research: Proceedings of Forum on November 1, 1997, National Academy of Sciences, Washington, D.C., National Academy Press, 58 pp. (1998). [On [Web](#)]

Board on Biology, National Research Council, Designing an Agricultural Genome Program, National Academy Press, 50 pp. (1998). [On [Web](#)]

Robert Pool and Joan Esnayra, *Bioinformatics: Converting Data to Knowledge: Workshop Summary*, Board on Biology, National Research Council, 54 pp. (2000). [On [Web](#)]

Title: Community College Initiative and Genome Educators

P.I.: Sylvia Spengler, Lawrence Berkeley National Laboratory

Project Period: 10/1/94 to 9/30/99

Products:

Four-week summer residential programs for students.

Seminars for biotechnology instructors.

Sabbatical fellowships.

Summer faculty-student research teams.

Title: Genes That Make News--News That Makes Genes: The Genetics of Complex Traits, held December 1994

P.I.: Jonathan Beckwith, Harvard University

Project Period: 11/01/94 to 10/31/95

Products:

Bound packet of articles for attendees.

J. Beckwith and J.S. Alper, "Human Behavioral Genetics," *Genet. Resour.* **10**(2), 5-9 (1996).

Title: Nontraditional Inheritance: Genetics and the Nature of Science Instructional Materials for High School Biology

P.I.: Joseph McInerney, Biological Sciences Curriculum Study

Project Period: 2/01/95 to 3/31/98

Products:

Joseph McInerney et al., *The Puzzle of Inheritance: Genetics and the Methods of Science*, Biological Sciences Curriculum Study, Colorado Springs, Colorado. Teaching module.

Title: Science + Literacy for Health: Human Genome Project

P.I.: Maria Sosa, American Association for the Advancement of Science

Project Period: 2/01/95 to 6/30/99

Products:

Catherine Baker, *Your Genes, Your Choices: Exploring the Issues Raised by Genetic Research*, American Association for the Advancement of Science (1997). Available in print and on the [Web](#).

Title: Genome Radio Project

P.I.: Barinetta Scott, Matt Binder, and Jude Thilman, Soundvision Productions

Project Period: 3/15/95 to 3/31/99

Products:

Nine 1-hour documentaries broadcast on public radio in the fall of 1998.

Web Site: <http://www.dnfiles.org>

Title: Publish Proceedings of Human Genome Project Conference: Shaping Scientific Public Policy, held November 1994

P.I.: Betsy Fader, Student Pugwash

Project Period: 5/01/95 to 11/30/95

Products:

Proceedings published.

Title: Conference on Conflict of Interest in Biomedicine, held spring of 1995

P.I.: Eric Kodish, Case Western Reserve University

Project Period: 5/01/95 to 4/30/97

Products:

E. Kodish, P. Whitehouse, and T. Murray, "Conflict of Interest in University-Industry Research Relationships: Realities, Politics, and Values," *Acad. Med.* **71**(12), 1287–90 (Dec. 1996).

Eric Kodish, "Commentary: Risks and Benefits, Testing and Screening, Cancer, Genes, and Dollars," *J. Law Med. Ethics* **25**(4), 252–55, 230 (Winter 1997).

Title: Congressional Fellowship in Human Genetics

P.I.: Elaine Strass and Stephen Goodman, American Society of Human Genetics

Project Period: 6/01/95 to 5/31/00

Products:

AAAS fellowships for genetics professionals to spend a year as special legislative assistants on the staff of members of Congress or on congressional committees.

Maimon M. Cohen, "Eye on Capitol Hill," *ASHG Newsletter*, 4-5 (February 1996).

Maimon M. Cohen, "Eye on Capitol Hill," *ASHG Newsletter*, 4-6 (July 1996).

Mary Z. Peliás, "The View from the Hill," *ASHG Newsletter*, 4 (March 1997).

Mary Z. Peliás, "AAAS Congressional Fellow Report for Period 1996-97," *ASHG Newsletter*, 9-11 (July 1998).

"AAAS Fellow (Carol Greene), Final Report, 1999; "Judith L. Benkendorf, "A View from Capitol Hill," online in *ASHG Newsletter* (April 2000).

Title: Workshop on Molecular Methods for Genetic Diagnosis, held July 1995

P.I.: Eugene Rinchik, Sarah Lawrence College

Project Period: 6/01/95 to 5/31/96

Title: Implications of the Geneticization of Healthcare for Primary Care Practitioners

P.I.: Mary Mahowald, University of Chicago

Project Period: 7/01/95 to 6/30/98

Products:

National Conference on The New Genetics in Primary Care, Chicago, IL, held April 1997.

Mary B. Mahowald, Angela Sheuerle, and Timothy Aspinwall, *Genetics in the Clinic: Clinical, Ethical, and Social Implications for Primary Care*, Mosby (2001).

Lainie Friedman Ross, "Genetic Services for Children: Who Should Consent?" in *A Companion to Genethics: Ethics and the Genetic Revolution*, ed. J.C. Burley and J. Harris, Blackwell's Companions to Philosophy Series, Oxford, England (in press, 2000).

Greg A. Sachs, "Alzheimer Genetics and the Primary Care Physician," pp. 239-55 in *Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*, ed. Stephen G. Post and Peter J. Whitehouse, Johns Hopkins University Press (1998).

Margaret R. Moon and Lainie Friedman Ross, "Ethical Issues in the New Genetics," *Forum* 7(3), 57-66 (1997).

Title: Conference on Controlling Our Destinies: Philosophical, Historical, and Ethical Perspectives on the Human Genome Project, held October 1995

P.I.: Philip Sloan, University of Notre Dame

Project Period: 7/01/95 to 6/30/96

Products:

Philip Sloan, ed., *Controlling Our Destinies: The Human Genome Project from Historical, Philosophical, Social, and Ethical Perspectives*, University of Notre Dame Press, Notre Dame, Indiana (2000).

Title: Conference on Promoting and Managing the Application of Genome Research

P.I.: Thomas Field, Jr., Franklin Pierce Law Center

Project Period: 8/15/95 to 8/14/96

Products:

Conference Proceedings, *RISK: Health, Safety & Environment* 7(3), 1996.

Title: Privacy, Confidentiality, and New Genetic Technology

P.I.: Mark A. Rothstein, University of Houston

Project Period: 9/01/95 to 8/31/96

Products:

Mark Rothstein, "The Law of Medical and Genetic Privacy in the Workplace," Chapter 15 in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven and London (1997).

Mark Rothstein, "Genetic Secrets: A Policy Framework," Chapter 23 in Mark Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven and London (1997).

Title: *A Question of Genes: Inherited Risks*

P.I.: Graham Chedd and Noel Schwerin, Oregon Public Broadcasting

Project Period: 9/01/95 to 8/31/97

Products:

Two-hour PBS special shown September 16, 1997.

Video series (8 one-hour programs, 1998).

Educator's guide, teacher resources [<http://www.pbs.org/gene>].

Title: *Your World, Our World: Exploring the Human Genome* Teacher Resource Materials

P.I.: Jeff Davidson, Pennsylvania Biotech Association

Project Period: 9/01/95 to 2/28/99

Products:

Exploring the Human Genome, special issue of *Your World Our World*, Pennsylvania Biotechnology Association, State College, Pennsylvania (1996).

Teachers' guide, resources such as posters and handouts.

Title: *Collaboration Among the Health Effects, Life Sciences, and Energy Biosciences Research Programs*

P.I.: Paul Gilman, National Academy of Sciences

Project Period: 9/15/95 to 11/30/95

Title: *Stanford Human Genome Education Program*

P.I.: Lane Conn and Richard Myers, Stanford University

Project Period: 2/01/96 to 1/31/98

Products:

Laboratory-based curriculum modules for high school students, unpublished:

- Unit 1, "Exploring Genetic Conditions: Genes, Cultures, and Choices"
- Unit 2, "DNA Snapshots: Peeking at Your DNA"

M. Munn et al., "The Involvement of Genome Researchers in High School Science Education," *Genome Res.* 9(7), 697-607 (1999).

Title: *The Human Genome Project and Mental Retardation: An Educational Program*

P.I.: Sharon Davis, The Arc of the United States

Project Period: 2/1/96 to 1/31/99

Products:

Web Site: <http://www.thearc.org>

Presentations

Sharon Davis, "The Human Genome Project: Examining The Arc's Concerns Regarding the Project's Ethical, Legal, and Social Implications," Platform Presentation at the DOE Human Genome Program Contractor-Grantee Workshop VI on November 12, 1997.

Sharon Davis et al., "Technology in Genetics: The Danger of Knowing Too Much," *Exceptional Parent* (November 1997).

Reports and Fact Sheets (All published in print and on the Web site)

- *Genetic Issues in Mental Retardation*, Vols. 1-3.
- "An Introduction to Genetics and Mental Retardation," **1**(1), 1996.
- "Genetic Discrimination," **1**(2), 1996.
- "Genetic Testing, Screening, and Counseling: An Overview," **1**(3), 1997.
- "Protecting Genetic Privacy," **2**(1), 1997.
- "Fragile X Syndrome," **2**(2), 1997.
- "Gene Therapy and Mental Retardation," **2**(3), 1998.
- "Participating in Genetic Research: Considerations for People with Mental Retardation and Their Families," **3**(1), 1998.
- "Mental Retardation and Development Disabilities Research Centers: An Overview of Current Genetic Research," **3**(2), 1998.

Fact Sheets (Q&As)

- "Genetic Causes of Mental Retardation," 1996.
- "Facts About Genetic Discrimination," 1996.
- "Prader-Willi Syndrome," 1997.
- "PKU," 1997.

Title: Workshop on Individualizing Medicine Through Genomics: Ethical, Legal, and Social Challenges

P.I.: Henry T. Greely, Stanford University

Project Period: 3/01/96 to 5/30/99

Products:

Videotapes of conference.

Title: *The Gene Letter*: An Online Newsletter on Ethical, Legal, and Social Issues in Genetics for Interested Professionals and Consumers

P.I.: Dorothy Wertz and Philip Reilly, Shriver Center

Project Period: 4/01/96 to 3/31/00

Products:

Videos, CD-ROMs, and Online Sites

Ten issues of *The Gene Letter* published online to May 1999.

Web Site: <http://www.geneletter.com>

Title: Series of Congressional Seminars on the Human Genome Project

P.I.: Mark Frankel, American Association for the Advancement of Science

Project Period: 4/15/96 to 8/14/97

Products:

Five seminars held between February and June 1996.

Title: Workshop on Ethical, Legal, and Social Implications of the Human Genome Project: Education of Interdisciplinary Professionals, held June 1996

P.I.: Joan O. Weiss, Alliance of Genetic Support Groups (now Genetic Alliance)

Project Period: 6/01/96 to 5/31/97

Products:

J. O. Weiss and E. V. Lapham, *Ethical, Legal, and Social Implications of the Human Genome Project: Education of Interdisciplinary Professionals* (1996), workshop proceedings.

Meeting culminated in a 3-year project (called HuGEM) sponsored by the ELSI branch of the NIH National Human Genome Research Institute. HuGEM produced a training video, manual, many educational and resource tools, a number of publications, and two core university courses.

Title: Special Issue on Genetics and Women's Health for *Journal of the American Medical Women's Association*

P.I.: Wendy Chavkin, American Medical Women's Association

Project Period: 8/15/96 to 8/14/97

Products:

J. Amer. Med. Women's Assoc. **52**(1), Winter 1997 issue.

Title: First International Conference on DNA Sampling and Human Genetic Research: Ethical, Legal, and Policy Aspects, held September 1996

P.I.: Bartha M. Knoppers, University of Montreal

Project Period: 8/15/96 to 8/14/97

Products:

GELS meeting in Washington, D.C., and subsequent submissions to European international authorities.

Bartha M. Knoppers, Claude M. Laberge, and Marie Hirtle, eds., *Human DNA: Law and Policy*, Kluwer Academic Publishers, Netherlands (1997).

Sonia Le Bris and Bartha M. Knoppers, "International and Comparative Concepts of Privacy," Chapter 22 in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, ed. Mark Rothstein, Yale University Press, New Haven and London (1997).

B. M. Knoppers, "Privacy, Confidentiality, and Genetic Information: A Comparative Analysis," *Microb. Compar. Genomics* **1**(2), 37-51 (1997).

B. M. Knoppers et al., "Control of DNA Samples," *Genomics* **50**, 385-401 (1998).

R. Chadwick et. al., "Legal Rights and Human Genetic Material," *Bioethics* **12**(4), 343-45 (1998).

Title: Tuskegee Genome Conference: The Human Genome Project and Its Relevance to the African-American Community, held September 1996

P.I.: Edward J. Smith, Tuskegee University

Project Period: 9/01/96 to 8/31/97

Products:

Edward Smith and Walter Sapp, eds., *Plain Talk About the Human Genome Project*, Tuskegee University Press, Tuskegee, Alabama (1997).

Title: Getting the Word Out on the Human Genome Project: A Course for Physicians

P.I.: Sara L. Tobin, Stanford University

Project Period: 9/01/96 to 3/31/00

Products:

Web site: <http://www.twistedladdermedia.com>

Two CD-ROMs released in 2001:

- *The New Genetics: Courseware for Physicians. Molecular Concepts, Applications, and Ramifications* (offers Continuing Medical Education credit to physicians).
- *The New Genetics: Courseware for Physicians. Molecular Concepts, Applications, and Ramifications*

P. J. Fox, S. E. Kelly, and S. L. Tobin, "Defining Dementia: Social and Historical Background of Alzheimer Disease," *Genet. Testing* 3, 13–19 (1999).

S. L. Tobin, N. Chun, T. M. Powell, and L. M. McConnell, "The Genetics of Alzheimer Disease and the Application of Molecular Tests," *Genet. Testing* 3, 37–45.

S. S. Jeffrey, T. M. Powell, and S. L. Tobin, "Clinical and Genetic Aspects of Breast Cancer," chap. 4 in *Genetic Testing for Inherited Susceptibility to Breast Cancer* (working title). In press, Cambridge University Press (2001).

S. L. Tobin and S. S. Jeffrey, "Cancer as a Genetic Disease," chap. 5 in *Genetic Testing for Inherited Susceptibility to Breast Cancer* (working title). In press, Cambridge University Press (2001).

S. L. Tobin and B. J. McCarthy (2001), "The Technology of Mutation Detection and Its Commercial Application," chap. 6 in *Genetic Testing for Inherited Susceptibility to Breast Cancer* (working title). In press, Cambridge University Press (2001).

Platform presentation at the DOE Contractor-Grantee Meeting VI, held in Santa Fe, New Mexico, in November 1997.

Title: Microbial Literacy Collaboration: Intimate Strangers: Unseen Life on Earth

P.I.: Cynthia Needham, American Society for Microbiology

Project Period: 12/01/96 to 2/29/00

Products:

Educational Web Site: <http://www.microbeworld.org>

Intimate Strangers: Unseen Life on Earth: Four-part science documentary due for national broadcast on PBS in the fall of 1999. Companion book.

Microbe World: Set of activities exploring the microbial world.

MicrobeWorld Mentors: Youth leadership conferences to develop microbial mentors.

Unseen Life on Earth: Telecourse based on concepts in the documentary.

Cynthia A. Needham et al., *Intimate Strangers: Unseen Life on Earth*, American Society for Microbiology (2000).

Title: Science and Issues of Human DNA Polymorphisms: An ELSI Training Program for High School Biology Teachers

P.I.: David Micklos, Cold Spring Harbor Laboratory
Project Period: 1/15/97 to 1/14/00

Products:

Web Site: <http://www.dnalc.org/>

Nine 2.5-day training workshops for high school science teachers

- October 24-26, 1997, Mt. Sinai School of Medicine, New York, New York
- November 8-10, 1997, Boston University School of Medicine, Boston, Massachusetts
- November 14-16, 1997, Canada College, Redwood City, California
- December 5-7, 1997, Morehouse College, Atlanta, Georgia
- March 26-28, 1998, Eccles Institute, University of Utah, Salt Lake City, Utah
- November 12-14, 1998, Mills Godwin Specialty Center, Richmond, Virginia
- December 3-5, 1998, University of Denver, Denver, Colorado
- January 9-11, 1999, California Lutheran University, Thousand Oaks, California
- March 26-28, 1999, Fred Hutchinson Cancer Center, Seattle, Washington

Three Advanced Technology (AT) PCR kits developed to simplify lab techniques in educational settings. Released through Carolina Biological Supply company in 1998.

Laboratory-based unit on polymorphisms (genetic differences) and the ELSI aspects of the genome project. Used in 3-day workshops for teachers.

Title: Genes, Environment, and Human Behavior: Development of Educational Materials for High School Biology

P.I.: Joseph P. McInerney and Mark Bloom, Biological Sciences Curriculum Study
Project Period: 2/01/97 to 1/31/00

Products:

Joseph McInerney et al., *Genes, Environment, and Human Behavior*, Biological Science Curriculum Study, Colorado Springs, Colorado (1999). Teaching module distributed free to high school teachers.

J. D. McInerney, "Genes, Behavior, and High School Biology," *Am. Biol. Teach.* **60**(3), 168-73 (1998).

Title: The Human Genome Project: What's the Public Got to do With It? A Symposium at the 1997 AAAS Annual Meeting and Scientific Innovation Exposition, held February 1997

P.I.: Gregory and Alexander Fowler, American Association for the Advancement of Science
Project Period: 2/15/97 to 2/14/98

Four cassettes of symposium (Parts 1 and 2) available from AAAS.

Title: The Human Genome Project: Reaching the Minority Communities in Maryland, held June 1997

P.I.: Raymond Zilinskas, University of Maryland
Project Period: 2/15/97 to 2/14/99

Products:

R. Zilinskas, ed., *Proceedings of the Conference on Ethical, Political, and Social Implications of the Human Genome Project for the Minority Communities of Maryland* (1999).

Raymond A. Zilinskas and Peter J. Balint, eds., *The Human Genome Project and Minority Communities: Ethical, Social, and Political Dilemmas*, Praeger Publishers, Westport and London (2001).

Title: Hispanic Role Model and Science Education Outreach Project: Human Genome Project Component

P.I.: Clay Dillingham, Self Reliance Foundation

Project Period: 3/01/97 to 2/29/00

Products:

About 100 new episodes of Spanish episodes to be broadcast over 2 years in three popular radio series, including talk shows in the United States and Latin America.

Bilingual 800 number for outreach information and referral service.

Syndicated column in 82 Spanish-language newspapers.

Title: Measuring the Effects of a Unique Law Limiting Employee Medical Examinations to Job-Related Matters

P.I.: Mark A. Rothstein, University of Houston

Project Period: 4/01/97 to 3/31/99

Products:

M. Rothstein, B. Gelb, and S. Craig, "Protecting Genetic Privacy by Permitting Employer Access Only to Job-Related Employee Medical Information: Analysis of a Unique Minnesota Law," *Am. J. Law Med.* **24**, 399-416 (1998).

Title: National Bioethics Advisory Commission

P.I.: William Raub, National Institutes of Health

Project Period: 4/01/97 to 7/31/99

Title: Electronic Scholarly Publishing: Foundation of Genetics

P.I.: Robert J. Robbins, Jr., Fred Hutchinson Cancer Research Center

Project Period: 5/01/97 to 4/30/00

Products:

Web Site: <http://www.esp.org>

Numerous classic papers in genetics republished electronically in a variety of formats, along with additional biographical, autobiographical, historical, pedagogical, and analytical material.

Title: *Genetics in the Courtroom* Issue of *Judges' Journal*

P.I.: J. Washington and Frederic G. Melcher, American Bar Association

Project Period: 7/01/97 to 6/30/98

Products:

Judges' J. **36**(3), Summer 1997 (entire issue devoted to genetic revolution's impact on society). Selections on the [Web](#).

Title: Confidentiality Concerns Raised by DNA-Based Tests in the Market-Driven Managed Care Setting

P.I.: Jeroo Kotval, State University of New York, Albany

Project Period: 7/15/97 to 4/14/00

Products:

Jeroo S. Kotval, "Market-Driven Managed Care in the Confidentiality of Genetic Tests: The Institution as Double Agent," *Albany Law J. Sci. Technol.* **9**(1), 1998.

Title: Bioavailability Policy Project

P.I.: Don Ritter, National Environmental Policy Institute

Project Period: 8/01/97 to 7/31/98

Title: Symposium on Human Genome Research: Implications for Health in Latin America, held November 1997

P.I.: Peter Main, International Federation of Institutions for Advanced Study

Project Period: 9/01/97 to 8/31/98

Title: Conference on Biotechnology and the Law: New Perspectives on Public Access and Proprietary Rights, held February 1998

P.I.: Robert P. Merges, University of California, Berkeley

Project Period: 1/01/98 to 12/31/98

Title: *Truth and Justice: Science and Its Appeals*: A Three-Hour Television Documentary for National PBS

P.I.: Noel Schwerin, Backbone Media

Project Period: 1/01/98 to 6/30/01

Products:

Program in preparation, 1998-2001.

Title: The Human Genome Project: Science and Social Change in the 21st Century, held April 1998

P.I.: David C. Page, Whitehead Institute for Biomedical Research

Project Period: 1/01/98 to 12/31/98

Products:

P. R. Reilly and D. C. Page, "We're Off to See the Genome," *Nat. Genet.* **20**, 15-17 (1998).

The Human Genome Project: Science, Law, and Social Change in the 21st Century, Whitehead Institute for Biomedical Research and the American Society of Law, Medicine, and Ethics (CD-ROM 1998).

Title: Genes and Society: Impact of New Technologies on Law, Medicine, and Policy, held May 2000

P.I.: David C. Page, Whitehead Institute for Biomedical Research

Project Period: 1/01/00 to 12/31/00

Products:

Genes and Society: Impact of New Technologies on Law, Medicine, and Policy, Whitehead Institute for Biomedical Research and the American Society of Law, Medicine, and Ethics (Whitehead Policy Symposium Report and CD-ROM, 2000).

Title: The Responsibility of Oversight in Genetic Research: How to Enable Effective Human Subject Review of Public and Privately Funded Research Programs

P.I.: Barbara Handelin, Prim&R

Project Period: 2/15/98 to 2/14/00

Products:

Video showing roundtable discussion by members of the Institutional Review Board community and the biopharmaceutical industry on hot topics in the ethical review of human genetics research.

Set of documents.

Title: Second International Conference on DNA Sampling: The Commercialization of Genetic Research: Ethical, Legal, and Policy Issues

P.I.: Timothy Caulfield, University of Alberta

Project Period: 7/15/98 to 7/14/99

Products:

T. Caulfield and B. Williams-Hones, eds., *The Commercialization of Genetic Research*, Kluwers Academic/Plenum Publishing, New York (1999).

Title: Conference on Informed Consent in Human Subject Research, held October 1998

P.I.: Rubye Prigmore Torrey, Tennessee Technological University

Project Period: 9/15/98 to 9/14/99

Products:

Proceedings of the Conference on Informed Consent in Human Subjects Research, 54 pp. (2000).

Title: An Economic Analysis of Intellectual Property Rights Issues Concerning the Human Genome Program

P.I.: David Bjornstad

Project Period: 10/01/98 to 9/30/99

Products:

Numerous papers in preparation (2001).

"Economic Implications of Intellectual Property Rights and the Human Genome Research Program," paper presented at the Fourth Annual Challenges in Licensing and Intellectual Property Symposium of the Licensing Executive Society, March 25, 2000.

"Economics and Human Genome Intellectual Property Rights--An Uncommon Topic," talk presented at at the Fourth Annual Challenges in Licensing and Intellectual Property Symposium of the Licensing Executive Society, March 25, 2000.

Title: Meeting on Whose Genes are They--Will the Courts Know? The Impact of Genetics on Justice

P.I.: Sandra Ratcliff Daffron, American Judicature Society

Project Period: 3/01/99 to 2/29/00

Title: Conference on the Human Genome Project for Minority Communities in the State of Louisiana, held April 1999

P.I.: Rosalind Hale, Zeta Phi Beta Sorority

Project Period: 3/15/99 to 3/14/00

Products:

Numerous workshops conducted by conference participants at minority meetings around the country.

Title: Human Genome Project Information Conference. Challenges and Impact of Human Genome Research for Minority Communities, held July 2000 in Philadelphia

P.I.: Kathryn Malvern, Zeta Phi Beta Sorority National Educational Foundation

Project Period:

Products:

Numerous workshops conducted by conference participants at minority meetings around the country.

The Challenges and Impact of Human Genome Research for Minority Communities, Conference Proceedings, 62 pp. (2000). Proceedings on [Web](#).

Title: Science Literacy Workshops for Public Radio

P.I.: Barinetta Scott, Soundvision Productions

Project Period: 5/01/99 to 8/31/01

Products:

Pilot week-long science training workshop for public radio reporters and producers held in October 1999 to introduce basic science concepts and offer training in science journalism.

Intensive week-long workshop held in March of 2001 at KQED in San Francisco for about a dozen media professionals from around the country. Scientists from a range of disciplines spoke on timely science topics.

Title: Dilemmas in Commercializing Human Genome and Biotechnology Products; Developing a Case-Based Business Ethics Curriculum for Industry

P.I.: Barbara Koenig, Stanford University

Project Period: 5/01/99 to 4/30/00

Products:

Business Ethics in the Biotechnology and Pharmaceutical Industries (working title), in preparation (2001).

Ten case studies developed for teaching business ethics and social issues in biotechnology and pharmaceutical industries. Originated in a business ethics course at Stanford University School of Medicine and Graduate School of Business, case studies were evaluated by use in a business school course, then modified and edited for inclusion in a textbook.

Case Study Companies and Topics

- Novartis - Conflicts of interest in academic plant genomics research collaboration.
- Celera Genomics - Corporate ownership of human genetic information.
- Adiana - Corporate responsibility for subjects harmed in clinical research.
- Genzyme - Use of placebo controls in xenotransplantation neurosurgery clinical trials.
- VaxGen - AIDS vaccine trials in Third World countries.
- Geron - Use of corporate ethics advice.
- PPL Therapeutics - Xenotransplant product safety.
- OncorMed/Myriad - Comparison of BRCA gene test marketing.
- Merck - Patient access to limited supplies of an AIDS drug.
- Zeneca - Direct-to-consumer advertising of drug to prevent breast cancer.

Companion book, in progress (2001).

Title: Democratizing the Human Genome Project: A Model Program for Education, Information, and Debate in Public Libraries

P.I.: Miriam Pollack, North Suburban Library System, Chicago, Illinois

Project Period: 9/1/00 to 8/31/02

Products:

Web site: <http://www.nsls.info/genome/>. Kickoff panel discussion on videotape, broadcast on TV. Three newsletters published, also on Website. Eleven participating libraries conducting a series of programs extending through summer 2002.

Title: Investigation of the Ethical Concepts that Inform the Laws Limiting Genetic Screening in Employment Decisions: Privacy, Human Dignity, Equality, Autonomy, and Efficiency

P.I.: Lynn Pasquerella and Lawrence Rothstein, University of Rhode Island, Kingston

Project Period: 9/1/00 to 8/31/02

Products:

"Genetics, Ethics, and Democracy: Ethical Concepts in Lawmaking Concerning Genetic Technology," paper presented at the Nature and Technology Conference of the Society for Philosophy and Technology conference in Aberdeen, Scotland, in July 2001.

Data gathered from state legislative commissions, departments of health, genetics groups, and individual state legislators (2001).

Title: Identifying and Accommodating Tribal Ethical, Moral, Cultural, and Legal Issues Related to the Human Genome Project

P.I.: Mervyn Tano, International Institute for Indigenous Resource Management, Denver, Colorado

Project Period: 10/1/00 to 9/30/03

Products:

Brett Shelton, "Regulating Genetic Research in Indian Country: Nature, Scope and Limitations of Tribal Authorities," paper for Seventh International Congress of Ethnobiology, Athens, Georgia (2000).

David Stephenson, Jr., "Lease, Contract, and License: An Introduction to Alternative Mechanisms for Protecting the Intellectual Property of American Indians," paper for Seventh International Congress of Ethnobiology, Athens, Georgia (2000).

David Stephenson, Jr., "Contracts and Licenses for Genetic Information: An Introduction to Alternative Mechanisms for Protecting the Intellectual Property of American Indians in the Context of the Human Genome Project," paper for First Conference of the University of Colorado Health Sciences Center ELSI Working Group, Aspen, Colorado (2001).

Kimberly TallBear, "Genetics, Culture, and Identity in Indian Country," paper for Seventh International Congress of Ethnobiology, Athens, Georgia, (2000).

Kimberly TallBear, "Racialising Tribal Identity and the Implications for Political and Cultural Development," paper for Indigenous Peoples and Racism Conference, Sydney, Australia (2001).

Kimberly TallBear, "Genetics, Race, and Tribes: Implications for Political and Cultural Sovereignty," paper for First Conference of the University of Colorado Health Sciences Center ELSI Working Group, Aspen, Colorado (2001).

Mervyn L. Tano, "Tattooed Heads, Scalps, Kidneys and Genetic Material: A Brief History of Commerce in Body Parts and the Implications for Regulating the Genome of Indigenous Peoples in Indian Country," paper for Seventh International Congress of Ethnobiology, Athens, Georgia, (2000).

Co-Sponsor, First Conference of the University of Colorado Health Sciences Center ELSI Working Group, Aspen, Colorado (2001), conference report forthcoming.

Title: Bioinformatics and the Human Genome Project

P.I.: Mark Bloom, Biological Sciences Curriculum Study, Colorado Springs, Colorado

Project Period: 9/1/00 to 8/31/02

Products: Bioinformatics module in preparation, 2001.

Title: Genetics and the Courts: Judicial Conference for Maine, New Hampshire, and Vermont

P.I.: Elizabeth Hodges, Administrative Office of the Courts, Concord, New Hampshire

Project Period: 9/1/00 to 8/31/01

Products: Conference held October 2000 for judges from three states.

Title: Science Education on the Internet. Conferences for Developers of Online Curricula

P.I.: Ray Gesteland, University of Utah, Salt Lake City

Project Period: 8/15/99 to 8/14/01

Products: Two national workshops held in November 1999 and 2000 for content developers of science-education Web sites. Workshop proceedings on Web "Learning Strategies for Science Education Websites," (2000).

Title: "All Not Fit to Breed": Survivors of America's First Eugenics Movement

P.I.: Mary Bishop, Virginia Polytechnic Institute and State University, Blacksburg

Project Period: 9/1/00 to 8/31/01

Products: Experiences of about 10 survivors being collected and preserved (2001).

Title: ELSI Perspectives in Genetically Complex Disorders and Workplace Exposure

P.I.: Laura Roberts, University of New Mexico, Albuquerque

Project Period: 9/1/00 to 8/31/01

Products: "Ethics, Psychiatric Genetics, and Mental Illness Research," presentation at Central Nervous System Summit 2001, Feb. 13, 2001.

Title: Pilot Conference on Genetics for the Clergy, Held April 2001

P.I.: Paul Sullins, Catholic University, Washington, D.C.

Project Period: 5/15/00 to 5/13/01

Products: Conference held April 25–27, 2001. White paper in preparation (2001).

Title: Genetics, Mental Illness, and Complex Diseases: Development and Distribution of an Interactive CD-ROM for Genetic Counselors

P.I.: Joseph McInerney Project

Period: 9/30/00 to 9/29/02

Products: CD-Rom in preparation for use by genetic counselors and secondary audiences (2001).

WORKING GROUPS AND MEETINGS

DOE-NIH ELSI Working Group Task Force on Genetics and Insurance Report published May 1993.

Analysis of Interpretation of the Americans With Disabilities Act by the Equal Employment Opportunity Commission Guidance issued March 1995.

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